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Dr. David Hamburg, President  
AAAS  
1515 Massachusetts Avenue NW  
Washington, DC 20005 USA

Dear Dr. Hamburg!

I hope you remember me from the first group of Human Biology students at Stanford who worked at Gombe, along with Nancy Merrick, Craig Packer, and Cay Craig. You might be interested to hear the story of one HumBio graduate.

My "career" has continued along Human Biologic lines. From Stanford I went to University of Florida to work on tropical ecology with John Ewel, and took a PhD on the ecological advantages of traditional mixed cropping systems in Tanzania after 2 years field work in Morogoro. In Tanzania I also met and fell in love with a Norwegian forester; we married in 1981 and I moved to Norway with a NATO postdoc on human disturbance of high mountain vegetation. Since then we have gotten 2 wonderful girls, Karen (1 yr) and Anna Mari (2½) and I have continued to work at the University of Oslo as a researcher in a Norwegian development aid project on management of lateritic soils in Zambia. That project will soon be finished and I will work at a nearby Junior College -- organizing and teaching 2 courses, Human Ecology and Ecology. In case anyone should ask, HumBio has been a superb background for all of these pursuits!

There are a few times in life when you have to ask friends for help, and this is one of those times for me. I feel guilty about taking your precious time with this, but it a vitally important matter, to us, so I suppress this feeling and ask.

Today my husband, Harald, and I got some bad news. Problems with bronchitis for many years and shortness of breath recently brought him to a respiratory specialist, Dr. Lien, at our local hospital in Skien (in southern Norway). Harald's blood test showed a deficiency of  $\alpha_1$ -antitrypsin (.5 g/l, <50% of normal), which explained his symptoms of a rather advanced pulmonary emphysema ( $FEV_1 = 1.2$ ,  $PEF = 290$ ). Dr. Lien suggested that this carried a prognosis of about 3-12 years, with increasing disability as the disease progresses. Lien had read of very promising clinical tests with replacement therapy for the missing protein with various forms of synthetic and extracted  $\alpha_1$ -antitrypsin, and tests with danazol, which also is effective in raising serum levels of  $\alpha_1$ -antitrypsin. Neither has been fully tested and approved for use in this context (and they will take several more years to come to Norway after they are approved in the US). There are also some technical problems to produce enough of the replacement  $\alpha_1$ -antitrypsin. The clinical trials are being done by a group led by Dr. Ronald D. Crystal and Dr. James E. Gadek, Pulmonary Branch, National Heart Lung and Blood Institute and Blood Bank, Clinical Center, National Institute of Health, Bethesda Md.

I am not very familiar with referral procedures either within the US or from the outside, but the question is: is there any chance of getting Harald into one of these trials, or at least in a position to receive the drug(s) as soon as they become available? Can you suggest how I should proceed to approach this research group? Is there any chance of being taken on as a patient if I

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write to Crystal and Gadek directly? I realize that your field of specialization lies somewhat above the lungs, but I thought it was worth asking what you would do in this situation and if you could help get us in contact, either with the research group at NIH, or another pulmonary specialist who could help. We are financially prepared to come to the States repeatedly for treatment (well, not every week!) and to cover all costs.

You don't suppose it could be of academic interest to have a case that's of pure northern-European origin, since many forms of the mutant exist?

We will be grateful for any suggestions you may have about how we should proceed.

Despite the circumstances I am really glad to have had an excuse to take contact with you again.

With warmest best wishes for the New Year,

A handwritten signature in cursive script that reads "Faye Benedict". The signature is written in dark ink and is positioned above the printed name.

Faye Benedict